

## Freedom of Information request 379-22

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### Request and Response

Q1. Within your trust, how many patients currently have a diagnosis for:

- Fabry Disease ICD10 code (E75.21) or Gaucher Disease (ICD10 code E75.22) <5
- Pompe Disease (ICD10 Code E74.02) 0
- Pompe Disease (ICD1 Code E74.02) Infantile-onset (Patients Diagnosed before age 1) 0
- MPS II (Hunter Syndrome) (ICD10 code E76.1) 0

Clarification 18 August 2022 - instead of "have a diagnosis", use "receiving treatment"

NHS Borders use a diagnosis code for Other Sphingolipidosis which includes Fabry Disease & Gaucher Disease but does not identify the specific disease. This information is not held, as defined in Section 17, Freedom of Information (Scotland) Act 2002. However, we have recorded above that <5 patients currently have a diagnosis for either Fabry Disease ICD10 code (E75.21) or Gaucher Disease (ICD10 code E75.22).

Q2. Of the patients above, how many patients have been newly diagnosed within the past 3 months for:

- Fabry Disease ICD10 code (E75.21) 0
- Gaucher Disease (ICD10 code E75.22) 0
- Pompe Disease (ICD10 Code E74.02) 0
- Pompe Disease (ICD1 Code E74.02) Infantile-onset (Patients Diagnosed before age 1) 0
- MPS II (Hunter Syndrome) (ICD10 code E76.1) 0

Clarification 18 August 2022 - instead of "have a diagnosis", use "receiving treatment"

Q3. How many patients have been treated in the last 3 months with the following products:

- Replagal (agalsidase alpha) 0
- Fabrazyme (algalsidase beta) 0
- Galafold (migalastat) 0
- VPRIV (velaglucerase alfa) 0
- Cerezyme (imiglucerase) 0
- Cerdelga (eliglustat) 0
- Zavesca (miglustat) 0
- Myozyme (Alglucosidase alfa) 0
- Nexvazyme (Avalglucosidase alfa) 0
- AT-GAA 0

Q4. Do you participate in any clinical trials for Pompe Disease? If so, can you please provide the name of each trial along with the number of patients taking part?

NHS Borders do not participate in any clinical trials for Pompe Disease.

Q5. Do you participate in any clinical trials for MPS II (Hunter Syndrome)? If so, can you please provide the name of each trial along with the number of patients taking part?

NHS Borders do not participate in any clinical trials for MPS II (Hunter Syndrome).

Please note that as NHS Borders is such a small Board and the number in some areas are very small, to provide further details could allow individuals to be identified and we would be in breach of the Data Protection Act 2018. We are therefore withholding all other data under Section 38(1)(b) of the Freedom of Information (Scotland) Act 2002. This is in accordance with the Code of Practice for Official Statistics which states that any number that is less than five; actual numbers and potentially identifiable information is withheld to help maintain patient confidentiality due to potential risk of disclosure. Further information is available in the ISD Statistical Disclosure Control Protocol.

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or [foi.enquiries@borders.scot.nhs.uk](mailto:foi.enquiries@borders.scot.nhs.uk).

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **379-22** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.